National MCH Center for Child Death Review Meeting
Sunday, September 7, 2003
Obtaining and Using Case Information
Moderator:
Mary Overpeck, HRSA, MCHB
Shkeda Johnson, HRSA, MCHB
Discussion Leaders:
Vick Zittle, Pennsylvania CDR
Debora Barnes-Josiah, Nebraska CDR

Ms. Johnson opened the session by having the attendees introduce themselves by sharing their name, where they were from and identifying the issue or issues that concerned them and /or sought to have answered at the conference. Among the attendees at both sessions, concerns included: identification of deaths; the case review process; confidentiality; the sharing of information both across jurisdictional lines and between agencies; including non-fatal cases in the review process; legal or policy obstacles; coordinating or integrating similarly focused groups (i.e. FIMR, Domestic Violence, Women's Mortality Review); obtaining the necessary records (especially educational, mental health); using and managing the collected data; managing the internal dynamics of a CDR team; case review; the "prevention piece"; and HIPAA.

The collection and sharing of data for case review and HIPAA seemed to draw the greatest interest with some feeling that HIPAA was confusing, unclear and had totally "messed everything up". Considerable frustration was expressed over teams inability to obtain relevant information from police, doctors, schools, hospitals, coroners --- even mandated information. Whereas this was an issue prior to HIPAA, it is of even more concern now, as there is significant reluctance to share information. Discussion resulted in a call for the National Center to provide direction, via perhaps a form letter, which could be sent to the appropriate individuals spelling out the law and the effect of HIPAA (a HIPAA standard), in terms of legitimizing the collection and sharing of case-relevant information. What is needed is for the CDR legislation to have "teeth".

Another concern was the sharing of information both intra and inter-state ---- cross-jurisdictional issues. Perhaps the National Center could work with State Registrars in addressing this problem along with getting State Registrars to provide copies of the death certificate "tape" in an effort to have better knowledge of the children who die. This led to some discussion of the terminology and definitions that ME's use on death certificates. To solve the jurisdictional difficulties several solutions were voiced: Invite the other state's team to your CDR meeting; request that the Medical Examiners from both states work together; explore cooperation from the Medical Examiner's Association.

There was interest in the functioning on teams: keeping the members focused, interested and committed and in encouraging the focus on prevention. This is particularly challenging in states where principle members of the team do not get along or trust one another. A contributing factor is the inability or reluctance to share case materials.

Regarding injury prevention, perhaps a "best practices" document should be shared among local CDR teams to motivate and enlighten the members.

Deaths to Native American children were discussed in terms of accessing data and jurisdictional issues, and the need for assistance from the FBI. One thought was to try to include tribal members and FBI personnel on the CDR teams or attempt to get the tribes to form their own CDR team to deal with the deaths in their tribes. It was noted that Federal law supercedes State law.